



QUOTES OF THE WEEK



"Some GPs are taking larger profits from their practices. That was never the intention of the new contract. I'm certainly surprised by individual GPs on over £200 000."

Health secretary Patricia Hewitt

"Patients don't need specialists to tell them they are fighting fit, most will know this themselves and those who want extra advice and reassurance would get this from their local GP."

"The current system needs a complete rethink; it is like asking a Michelin-starred chef to cook microwave meals all day, a waste of their skills and resources."

National Clinical Director for Primary Care Dr David Colin-Thomé on the plan to scrap routine consultant check-ups following elective surgery

"The irony of the one-size-fits-all proposal being suggested by the government is that patients will lose the right to see whom they choose to see, unless they are prepared to pay for the privilege. This flies in the face of the government's own choice agenda. It is time the government listens to those who know the NHS best—its doctors and patients, rather than those stuck in the ivory towers of policy-making."

Dr Jonathan Fielden, Chairman, BMA Consultants' Committee, quoted in the *Guardian*

"From Christmas onwards, I have been standing on my head."

Expectant mother Antje Grimm, one of many heavily pregnant German women said to be trying to delay giving birth until 1 January 2007, because a new law—to boost the flagging birth rate in Germany—will mean a difference of tens of thousands of pounds in benefits

Compiled by Rebecca Coombes, journalist, London
rcoombes@bmjgroup.com



THE WEEK IN MEDICINE

Medical records: are patients' secrets up for grabs?

What's happened?

The NHS's ill fated computer project has made the news again, this time over the government's climbdown from putting medical records on a national database.

With public confidence in the ongoing £20bn upgrade of NHS computer systems right down there with the government's handling of Iraq, the news that electronic medical records would not, as originally planned, be automatically uploaded to a central computer "spine" was mothers' milk to British newspapers. The security of the sinister sounding "spine" was the main focus of press concern. Do people want to risk others finding out they were a teenage bed wetter, or once had anal warts?

Under the initial proposals, summary patient records—including medicines taken, adverse reactions, and allergies—were to be made available for access nationally by GPs and hospitals. Under pressure, health minister Lord Warner produced a report the week before Christmas, promising patients an opt out. This softened approach would also allow patients to access and amend online records before they are sent to the national database.

What the papers say

The *Guardian*, which had been running a campaign against a compulsory national database of medical records, showed admirable self restraint on hearing of the climbdown. Instead of going with "it was the *Guardian* wot won it" headlines, it was almost downcast.

In a comment article, Ross Anderson, professor of security engineering at Cambridge University, warned that a lot more was at stake: "Don't break out the champagne yet. The [Warner] report was cleverly spun; hidden in an appendix is confirmation that you can opt out of the summary care record, but not the detailed care record."

Over the next few years, detailed care records (the whole medical record, which will replace GP and hospital records) will be uploaded to a regional hosting centre run by a government contractor. The chief medical officer will eventually be in control of the lot. The government is not offering such an easy opt-out here, Anderson warned, and

there will be plenty of opportunity to breach patients' privacy.

He said: "Once the records of millions of people are on one system, to which a court will give access without GPs' knowledge, the police will be sorely tempted. They already collect all sorts of operationally useful data: they have had access to opiate prescriptions for years, and there's been a steady rise in their requests for journey data from London's Oyster card [electronic ticketing] system."

Christina Odone, in the *Telegraph*, continued with the "thin end of the wedge" theme. She urged readers to write to their GP in order to opt out of "the latest and maddest drive to centralisation."

"Otherwise, our medical records—the sexually transmitted disease we kept a secret, the addiction to sleeping pills we overcame 10 years ago, the mental breakdown at university—will be loaded on one mammoth, central database."

In Odone's opinion, centrally available electronic patient records would "spell an end to privacy." What about all those millions of NHS employees who would have access to your data? And this is before we get started on the hackers. "As one NHS worker who emailed the *Today* programme confirmed, the NHS 'is as leaky as a sieve.' Something as big as the NHS centralised system is just the kind of headline-grabbing target hackers love to tackle," she wrote.

The *Times* found ample grist for the columnist's mill. Alice Miles, in an article ominously titled "Sending a shiver down my spine", was almost nostalgic that patients' experiences of "disappearing notes" could soon be a thing of the past.

"It has always been part of the NHS experience: turn up for long awaited outpatient appointment; consultant doesn't know your name, no one has given him your notes. Somewhere in the bowels of the hospital a porter is wheeling them around, spilling from bulging envelopes, with dozens of other patient records packed on to a trolley. They might get there, they might not," she wrote.

A little patience, please, said a *Guardian* leader. At least the government has shown some signs of having listened. When the

first information is uploaded in trials next year there will be clear, clinical advantages, but much more needed to be done to quell fears. The “sealed envelope” technology, for example, which allows patients to restrict access to parts of their record, is still at the planning and development stage, according to the Department of Health.

Seeking to look at both sides of the story, the *Independent* ran a Q and A: “The big question: should we fear plans to put medical records on a national database?”

“Ministers think these risks have been overplayed. They believe that the interests of the majority of elderly vulnerable patients who have most to gain from the new system are being drowned out by a vocal minority worried about the privacy aspects and the threat to confidentiality,” it said.

What happened next

Chancellor Gordon Brown will soon have to decide the fate of the NHS computer system. Don’t make it your Waterloo, warned the *Guardian* in a comment article. “The system is showing all the classic symptoms of turning into a software project disaster. The convoy is heading for the rocks. Gordon Brown will have to decide soon whether to scrap the central database and build safe systems that will work. If he calls it wrong—as with Blair and Iraq—it may well be the decision for which he is remembered,” it declared.

Rebecca Coombes, journalist, London
rcoombes@bmjgroup.com

“Something as big as the NHS centralised system is just the kind of headline-grabbing target hackers love to tackle”

Christina Odone,
Daily Telegraph



PHOTOS.COM

Paper records: will we miss them?

WHAT'S ON THE WEB LIBYAN HIV DEATH SENTENCES

“Quick background—in 1998, children began testing positive for HIV in a major hospital in Libya’s second-largest city, sparking a health crisis. An investigation found the infections occurred in an area where many Bulgarian nurses were assigned, and Libyan dictator Qaddafi accused health care workers of acting on the orders of the CIA and Israel’s Mossad. So far, so ridiculous. A Libyan court eventually convicted the six health professionals of intentionally infecting the children, despite extensive testimony that the virus predated the nurses’ arrival and was likely spread through the use of contaminated needles.”
[americablog.blogspot.com](#)

“We’ve heard yet again that the Libyan courts have upheld the death sentence of the Bulgarian nurses and Palestinian doctor who

were convicted of deliberately infecting 426 Libyan children with the HIV virus. Through the miracle of magnification we can actually hone in on the real culprits of this debacle . . . At 500X we have the naked HIV virus; at 2500X we have the HIV virus in much greater detail and one can see how the virus envelope is especially evolved to allow it to elude the human immune system; [and] at 50 000 X we have the world’s most wretched low life, in a golden muu muu. This pathogen will sanction the execution of trained health professionals.”
[talesfromthewomb.blogspot.com](#)

“Such madness does *not* help me in any way to want to help people in the form of foreign missions. Basically, if that’s the way they’re going to treat people, they can keep their HIV epidemic and deal with it

themselves. What went wrong is that they went to a country not known for its human rights, or fair justice system.”
[allnurses.com/forums](#)

“The prestigious journal *Nature* published an unusually strongly-worded denunciation of Libya’s attempt to scapegoat innocent people—‘Imagine that five American nurses and a British doctor have been detained and tortured in a Libyan prison since 1999, and that a Libyan prosecutor called at the end of August for their execution . . . on trumped-up charges of deliberately contaminating more than 400 children with HIV in 1998. Meanwhile, the international community and its leaders sit by, spectators of a farce of a trial, leaving a handful of dedicated volunteer humanitarian lawyers and scientists

to try to secure their release.’”
[majikthise.typepad.com](#)

“A Libyan Court sentenced 6 Bulgarian medics [sic] to death. And that’s because Gaddafi wanted these unfortunate guys to be bargaining chips in exchange for:

- the convicted Pan Am Flight 103 bomber Megrahi, serving a life sentence in a Scottish jail . . . to be released; and,
- US\$2.7bn compensation . . . paid to Libya for the care of the HIV-infected patients (the exact sum offered by Libya in compensation for the 270 lives lost in the 1988 Lockerbie bombing). Well, isn’t that kidnap for ransom?”
[www.alburbohol.net/blog](#)

Compiled by Balaji Ravichandran,
editor, *studentBMJ*
[bravichandran@bmj.com](#)

MEDICINE AND THE MEDIA

Sucked into the Herceptin maelstrom

Breast cancer patient and doctor **Jane Keidan** narrowly escaped being turned into a media star when campaigning to get prescribed Herceptin. Is this what patients seeking best treatment are now driven to?

I was diagnosed with HER2 positive breast cancer in August 2005. Before my diagnosis, I had little knowledge of the modern management of breast cancer and, like many patients, used online resources for information. The Breast Cancer Care website was running a campaign to make Herceptin (trastuzumab) available to all HER2+ women and I signed up. I simply could not understand from the data presented on the website and in the media why such an effective agent should be denied to women who, if they relapsed, would receive it anyway. The logic seemed flawed. I wrote letters to everyone—both primary care trusts (PCTs) in the area, the chair of policy at the Cancer Network, my member of parliament, the prime minister, the chief executives of the strategic health authority and the hospital trust—asking when and if the drug would be made available to me and other HER2+ women.

In the meantime, I was contacted by the *Sun* newspaper, whose health editor was championing the Herceptin campaign. She was interested in my story—I was both a doctor and a “cancer victim”—and ran an article about my case. The next day the women’s section was devoted to breast cancer. It included an emotive piece showing photographs of a number of women with HER2+ breast cancer, one of whom “would die if the drug were not made available.” But overall the issues were covered fairly. After this publicity I was asked to appear on the morning television programme, GMTV, to talk about Herceptin. But as this was very early on in my chemotherapy, I did not feel emotionally up to discussing the issues in person.

The Herceptin campaign rose to fever pitch as several women took their PCTs or trusts to court. Articles appeared almost daily in the press and featured on radio and television. I began to feel that if I did not receive this drug then I would have very little chance of surviving my cancer. At this stage I received replies to my various letters. A representative from the Department of Health replied and was sympathetic, but stated that the drug could not be made generally available until it was both licensed for use in early breast cancer and approved for this by NICE (the National Institute for Health and Clinical Excellence). I was assured that the health secretary, Patricia Hewitt, had requested the drug to be fast tracked by NICE, subject to licensing. The representative explained that the drug might be available to me in exceptional circumstances but this was a decision for the local PCT, and the health secretary had stated that “PCTs should not refuse to fund Herceptin solely on grounds of cost.” They also emphasised that “in the interim period between a drug being licensed and NICE guidance being available . . . the NHS should not refuse to fund specific drugs or treatments simply because they have not yet been appraised by NICE.”

The Cancer Network suggested that I ask my oncologist to submit a request for exceptional funding as Herceptin would not be available generally until the normal process of approval had occurred and this could take some time. Their letter was copied to the PCT. The PCT produced a standard letter stating that the drug would be available to women with early breast cancer in 9–12 months—too late for me—but I could have my individual case considered by the PCT on an exceptional named patient basis.

Throughout my treatment the health editor of the *Sun* kept in contact by telephone and emphasised that if I experienced difficulty obtaining Herceptin they would be willing to “push” on my behalf by contact-

ing the relevant PCT to “discuss the issue further.” However I was feeling demoralised by this stage and I decided to take no further action until I had completed my chemotherapy, when I hoped some of the questions about the drug would have been clarified. After finishing chemotherapy, I discussed Herceptin treatment with my oncologist. He expressed concerns about the long term cardiac effects which had emerged in studies but had received very little attention either on the Breast Cancer Care website or from the media. More careful analysis of the “50% benefit” which had been widely quoted in the medical and non-medical press (www.dh.gov.uk/assetRoot/04/12/63/84/04126384.pdf and *Pharm.J* 2005;274:605), and fixed in my mind, actually translated into a 4–5% benefit to me, which equally balanced the cardiac risk. So I elected not to receive the drug and will be happy with this decision even if my tumour returns.

This story illustrates how even a medically trained and usually rational woman becomes vulnerable when diagnosed as having a potentially life threatening illness. I believe much of the information about the use of Herceptin in early breast cancer was generated artificially by the media and industry, fuelled by individual cases such as mine.

Having been sucked into this maelstrom, I have concerns for the independent role of NICE and the PCTs, onto whom everyone seemed to load the final decision about availability of funding for such drugs in “exceptional cases.” What makes an “exceptional case”—publicity in the *Sun*, threats of court action? How are we to avoid this madness happening

with future agents? I don’t know the answer, but as a vulnerable person caught up in the middle of these events, I hope that a better solution can be found for patients and for our health service.

Jane Keidan is a consultant haematologist, Queen Elizabeth Hospital, King’s Lynn NHS Trust
Jane.Keidan@qehkl.nhs.uk



DR P MARAZZI/SPL

LIFE AND DEATH Iona Heath

In defence of a National Sickness Service

A reconstituted NHS that prioritises prevention of sickness would fail all those who are ill now

It has become commonplace to describe our current healthcare arrangements as a National Sickness Service and to call for a transformation to a genuine National Health Service that would prioritise prevention above cure. This is the sort of facile sloganeering, beloved of politicians and policymakers, that systematically ignores the implications of the rhetoric. The proposed transformation is already shifting the focus of health care away from the needs of the sick towards those of the well, from the old to the young and from the poor to the rich. Is this really what we want or need?

Societies fail whenever someone who succumbs to a treatable illness causing pain, suffering, or premature death is unable to avail themselves of effective treatment because of the lack of money to pay for it. In the context of heightened social solidarity immediately after the second world war, UK society set out to ensure that this situation would not arise again through the creation of the NHS. In 1948, Aneurin Bevan expressed this resolve: "We ought to take pride in the fact that, despite our financial and economic anxieties, we are still able to do the most civilised thing in the world—put the welfare of the sick in front of every other consideration." The proposal to move away from a National Sickness Service undoes this over-riding commitment to the welfare of the sick.

Relieving suffering is an enduring moral imperative; the contemporary obsession with maintaining health is part of the persistent, but recurrently illusory, human dream of controlling the future. The present day manifestation of this dream is mediated through science, with the new holy grail being a long life, devoid of suffering, and ending in extreme old age with rapid decline and death, also miraculously devoid of suffering. The pretence that this is deliverable by a reconstituted National Health Service

betrays all those who are suffering here and now.

Those who promulgate the dream vastly underestimate the role of luck and contingency in human health. They want to believe that health is a simple opposite of sickness, that it is in the gift of medical science, and that it can be delivered to order. Health becomes a commodity like any other, and it is clear that the rhetoric is underpinning the rapid commercialisation of healthcare and the exploitation of sickness and fears of sickness for the pursuit of profit. Doctors are colluding with politicians and journalists in the systematic exaggeration of the power of preventive medicine, with the dangerous and misleading suggestion that more can be done to promote health through reconstituting the health service than through reforming society. Despite all the emphasis on diet and exercise, the most powerful determinants of health remain wealth and happiness. The more equal distribution of hope and opportunity achieves more than the life long prescription of cholesterol lowering drugs and the stapling of stomachs. The emphasis on lifestyle risk factors for health implies that those who have had no luck are somehow morally deficient. This is both unnecessary and vindictive.

None of this is to deny the importance of preventive health interventions within clinical encounters, where there is much that can and should be done. Recent smoking cessation interventions have been very successful but, even with smoking, more can be achieved through taxation and by minimising smoking opportunities at work and in public places than through cajoling individuals. Immunisation campaigns and similar public health interventions have been hugely beneficial, but the current trend to define risk factors for ill health as diseases in themselves and therefore to define disease on the



“Doctors are colluding with politicians and journalists in the systematic exaggeration of the power of preventive medicine”

basis of a biometric number rather than an understanding of suffering is deeply worrying and is actively turning people into patients.

A National Health Service committed to prioritising the prevention of sickness above its treatment would accelerate the pursuit of biometric risk factors for this or that disease and the development of statistically effective treatments for each one in turn. This process legitimises investment in the wholesale drug treatment of healthy people and the increasing costs of this begin to pose a very real threat to the provision of universal healthcare systems that are available and accessible to all. No universal healthcare system, funded through taxation, can possibly pay for the pharmaceutical treatment of all risks to health. An excessive and unrealistic commitment to prevention of sickness could destroy our capacity to care for those who are already sick; everyone, in time, must become sick and die.

One of the ambitions of preventive health care is that it will reduce the gap between rich and poor, but health inequalities reflect wider societal inequalities and cannot be solved by a health service operating within a persistently unequal society. As Peter Skrabanek asked many years ago, why does poverty matter only when it creates illness and disease? Why are we not appalled by poverty because it is “cruel, demeaning and unjust” long before it manifests itself as ill health? Through recent advances in psychoneuroimmunology, we begin to understand how the chronic psychosocial stress of finding oneself at the bottom of society’s pile leads to compromised immunity, disordered metabolism, and premature disease. The primary solution should not be medication but a genuine commitment to fairness and justice in a humane society.

Iona Heath is a general practitioner, London iona.heath@dsl.pipex.com